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Palliative Care Gaps in Providing Psychological Treatment: A Review of the Current State of Research in Multidisciplinary Palliative Care

Elissa Kozlov, PhD¹, Bahar Niknejad, MD², and M. C. Reid, PhD, MD³

¹Weill Cornell Medical College, New York Presbyterian Hospital, New York, NY, USA

²Cornell University Joan and Sanford I Weill Medical College, New York, NY, USA

³Weill Cornell Medical College, New York, NY, USA

Abstract

Background—Patients with advanced illness often have high rates of psychological symptoms. Many multicomponent palliative care intervention studies have investigated the efficacy of overall symptom reduction; however, little research has focused explicitly on how interventions address psychological symptoms associated with serious illness.

Methods—The current study reviewed 59 multicomponent palliative care intervention articles and analyzed the mental health components of palliative care interventions and their outcomes in order to better understand the current state of psychological care in palliative care.

Results—The majority of articles (69.5%) did not provide any details regarding the psychological component delivered as part of the palliative care intervention. Most (54.2%) studies did not specify which provider on the team was responsible for providing the psychological intervention. Studies varied regarding the type of outcome measure utilized; multi-symptom assessment scales were used in 54.2% of studies, mental health scales were employed in 25.4%, quality of life and distress scales were used in 16.9%, and no psychological scales were reported in 28.8%. Fewer than half the studies (42.4%) documented a change in a psychological outcome.

Discussion and Conclusion—The majority of analyzed studies failed to describe how psychological symptoms were identified and treated, which discipline on the team provided the treatment, and whether psychological symptoms improved as a result of the intervention. Future research evaluating the effects of palliative care interventions on psychological symptoms will benefit from using reliable and valid psychological outcome measures and providing specificity regarding the psychological components of the intervention and who provides it.

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Corresponding Author: Elissa Kozlov, PhD, Weill Cornell Medical College, New York Presbyterian Hospital, 525 East 68th Street, Box 39, 1404 Baker Pavilion, New York, NY 10065, USA. elk2020@med.cornell.edu.

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ORCID iD

Elissa Kozlov <http://orcid.org/0000-0003-1027-2352>

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Introduction

Adults living with life-limiting or serious illnesses have significant symptom burden which is often unmet in our current system and contributes to diminished quality of life and poor health outcomes.^{1–3} Given the increasing number of adults living with serious or life-limiting illness, due in part to America's aging population, palliative care services have been expanding rapidly in the United States to help address unmet needs of this patient population.^{4,5} Palliative care, as defined by multiple organizations including the World Health Organization, is a holistic, multidisciplinary team-based approach to care for patients with serious illness and their families that is intended to address the physical, psychological, social, spiritual, and practical issues associated with illness and its treatment.⁶

Given the multiple domains that palliative care seeks to address, organizations such as the National Consensus Project and National Hospice and Palliative Care Organization have issued guidelines to facilitate delivery of care in these various domains (eg, ethical, cultural, physical, and psychological) as a way to help palliative care teams provide quality services to patients and their families. The guidelines specify that “the interdisciplinary team assesses and addresses psychological and psychiatric aspects of care based upon the best available evidence to maximize patient and family coping and quality of life.”⁷ Despite the existence of these guidelines and the clear mission to treat psychological symptoms in patients receiving palliative care, there is uncertainty regarding what psychological interventions are actually delivered, who provides the interventions, and whether these interventions are effective in reducing psychological symptom burden.

Generating knowledge in this area is critical because psychological distress is highly prevalent in patients with serious illness. For example, 30% to 40% of patients with cancer have diagnosable depression, anxiety, or another psychiatric disorder.⁸ Other serious illnesses, such as end-stage renal disease (ESRD), heart disease, and chronic obstructive pulmonary disease (COPD), have similarly high rates of mental health disorders, and multiple studies have documented significant levels of unmet mental health needs in these populations.^{9–11} Many more patients likely suffer from subsyndromal psychological distress. Furthermore, being diagnosed with a serious illness can lead to new psychological issues such as a desire for hastened death or existential difficulties and concerns about the legacy one leaves.^{12–14} Caregivers of patients with serious illness also suffer increased psychological burden and are at risk of developing mental health disorders such as anxiety and depression.^{15,16} Given the added psychological distress that is often associated with serious illness for both patients and their families, it is essential that palliative care teams comprehensively assess and treat mental health conditions in their target population.

Because psychological care is not exclusively the purview of any one discipline (compared to medical and nursing care, for example, which are customarily delivered by doctors and

nurses), it can be difficult to determine who on the team has primary responsibility for patients' and family members' psychological care. Indeed, all palliative care professionals are expected to have some training and competency in social support and psychological issues in patients with serious illness. However, there is a distinction between psychological support expected to be provided by all disciplines to all patients and psychological assessment and intervention for specific patients with mental health needs. The National Institute for Health and Clinical Excellence (NICE) issued a 4-level model (Figure 1) for psychological assessment and intervention that helps delineate the roles of palliative care providers and mental health specialists within palliative care.¹⁹ Per the NICE model, all providers should have basic skills in empathic listening and providing social support to all patients. As a patient's psychological symptoms become increasingly severe, providers with specific training and expertise in psychiatric assessment and treatment should be called upon to provide care. It remains unclear, however, whether this model is being integrated into palliative care teams' clinical practice. For example, palliative care teams may not be staffed with mental health-care professionals, and when there is no mental health expert on the team, it is unclear whether mental health specialists external to the palliative care team are called upon to provide psychological interventions to patients in need. While palliative care teams may be equipped to manage low-to-moderate levels of psychological distress through social supportive and empathic listening, patients with diagnosable psychiatric disorders or high levels of psychological symptoms across multiple domains would likely benefit from specialist intervention.

Although previous reviews have evaluated the efficacy of palliative care interventions as well as which domains of care are being offered to patients and their families,^{20–23} none have focused specifically on mental health interventions offered as part of palliative care. The current study analyzes the mental health components of palliative care interventions and their outcomes in order to better understand the current state of psychological care within palliative care.

Methods

Article Selection

See the study by Phongtankuel et al²³ for a full description of how articles were initially identified. Briefly, PubMed, OVID, MEDLINE, CINAHL, and Abstracts in Social Gerontology databases were searched and eligible articles published between January 1, 1980, and December 1, 2015, were retained for further analysis. The initial review identified a total of 64 articles that reported the results of various multicomponent palliative care interventions targeting patients with cancer, advanced heart disease, end-stage lung disease, ESRD, or some combination of these conditions. All of the articles were from the year 2000 or later.

The present study analyzed a subset of studies from the original review (59 of 64 articles or 92.2%) that had been identified as having a psychological component delivered as part of a multicomponent palliative care intervention.²² Data were abstracted and coded from each article by 2 investigators (Elissa Kozlov, Bahar Niknejad). A third investigator (Carrington Reid) abstracted data from a 10% random subsample of the 59 articles to establish the

reliability of the abstraction and coding process. The third abstractor had 100% interrater reliability.

Data Abstraction

Variables were abstracted according to a predetermined coding guideline. The variables included verbatim text of the description of the psychological component of the intervention, mental health scale utilized, discipline(s) providing the psychological intervention, whether additional training was provided for the discipline(s) providing the intervention, change in mental health outcome, effect size of mental health outcome, study design, study setting (ie, inpatient vs outpatient), and illness type. An effect size of the mental health outcomes was included in the data abstraction because the American Psychological Association Board of Scientific Affairs recommends that effect size be reported in all psychological studies.²⁴

Secondary coding of variables was conducted after reviewing the first 20 articles to further characterize the interventions and the outcomes. Verbatim intervention descriptions were further coded into categories based on their content description. For example, “nondescriptive intervention” was utilized when the data abstractor was unable to discern what type of psychological intervention was being delivered due to vague or nonspecific language, for example, “we provided psychosocial support.” In order for a study to be categorized as a “cognitive behavioral therapy (CBT)-based intervention,” the description of the intervention had to specifically reference cognitive behavioral therapy. In order for a study to be categorized as an “educational intervention,” the authors had to explicitly describe education as a core component of the intervention. For a study to be categorized as “other descriptive intervention,” the authors had to provide an explanation of the intervention that did not describe the intervention as purely educational or one utilizing a CBT framework. For example, the phrase “case managers help patients prepare for death psychosocially by enabling them to find closure in relationships and place their affairs in order” was classified in the category of “other descriptive intervention.” Finally, if a study described an intervention as having both an educational and CBT component or an educational and “other descriptive” component, the study was coded as a “CBT-based intervention” or “other descriptive” intervention since many psychotherapies include educational content as part of the treatment.

The types of mental health scales employed to assess for treatment effects in the analyzed studies were further coded to reflect the following categories: multi-symptom assessment, validated mental health scale, other, or none. A study classified as using “multi-symptom assessments” included one or more scales that assessed symptoms across multiple domains such as the Edmonton Symptom Assessment, the Short Form Health Care Survey 12 item (SF-12) or 36 item (SF-36), the Functional Assessment of Cancer Therapy, the Karnofsky, the Functional Assessment of Chronic Illness Therapy, the Symptom Check List, and the Palliative Care Assessment Tool. Articles classified as employing a validated mental health scale included studies that clearly measured one or more specific mental health domains, such as depression, anxiety, or mood, and had substantial literature supporting its validity and reliability, for example, the Beck Depression Inventory, Patient Health Questionnaire, Hospital Anxiety and Depression Scale, Center for Epidemiological Studies Depression

Scale, and State Trait Anxiety Inventory. The category of “other” included general quality of life assessments, general distress measurements, and nonvalidated scales such as “using numeric ratings from 1 to 10 to assess depression and anxiety.” The category “none” reflected studies that did not include any measures related to psychological outcomes.

Analyses

Frequencies were calculated in order to categorize the types of psychological interventions and their efficacy on the target population.

Results

Methods and Demographics of the Studies

The majority of studies (69.5%) evaluated palliative care interventions targeting patients with cancer, while 3.4% focused on patients with end-stage COPD, 10.2% on advanced heart disease, 3.4% on ESRD, and 13.6% on patients with some combination of these illnesses. Most studies were conducted in the inpatient setting (76.3%) compared to outpatient (18.6%), while 5.1% of the studies did not report the location of the intervention.

Fewer than half of the studies (42.4%) employed a randomized controlled trial design, 11.9% utilized an observational design, while the remaining 45.8% employed other designs, for example, cluster analyses of mixed methodology.

What Was the Psychological Intervention and Who Provided It?

A total of 69.5% of articles did not provide any details regarding the psychological component of the palliative care intervention evaluated in the study and were coded as “nondescriptive intervention”; 8.5% were coded as delivering a CBT-styled intervention, 11.9% were classified as delivering an educational intervention, while 10.2% were coded as other.

Psychological interventions were delivered by nurses in 27.1% of the studies, social workers in 3.4%, and psychologists in 3.4%; 54.2% of the studies did not specify which team member delivered the psychological component of the intervention; 18.6% explicitly stated that the individual delivering the psychological component of the intervention received training in how to deliver it.

How Was Efficacy Measured and Were the Psychological Interventions Effective?

Interventions were evaluated using a variety of scales. Table 1 lists the frequencies of the scales utilized; 28.9% of the studies did not utilize any psychological scale.

A change in the aforementioned variables in the expected direction was documented in 42.4% of studies. However, of these studies, only 13.6% studies utilized a mental health-specific scale. Only 1.7% of studies reported effect size.

Discussion

The results from this review suggest that the current state of mental health research within palliative care is lacking in scientific rigor and specificity with respect to the evaluated interventions. The vast majority of analyzed studies failed to adequately describe how psychological symptoms were identified and treated, which discipline on the team provided the treatment, and whether psychological symptoms improved as a result of the intervention.

Most studies indicated that “psychosocial support” was provided as part of the palliative care intervention. Although psychosocial support constitutes a critically important aspect of palliative care, this description is not well operationalized and therefore lacks clinical utility and research reproducibility. Most health-care providers would likely endorse that psychosocial support is part of the care they provide, especially within palliative care, but this does not necessarily translate to psychological symptom reduction. Furthermore, psychosocial support is not operationalized within the literature. For some providers, this may mean active listening, while for others, it could mean utilizing empathic statements or therapeutic touch. For others, it could include providing information and education. Without specifying what particular type of psychosocial support is being provided, clinicians and researchers are unable to meaningfully translate the results into practice. Furthermore, if a patient is experiencing severe symptoms of depression or anxiety that warrant a clinical diagnosis, they are likely to benefit from the numerous empirically supported psychological treatments available, such as cognitive behavioral therapy, to treat these symptoms, but it is not yet determined whether undefined psychosocial support will have an effect on relieving psychological symptoms of various severity or diagnosed psychiatric disorders.

Although some studies indicated which member of the palliative care team was responsible for providing the psychological component of the intervention, the vast majority of articles did not specify who on the team was responsible for assessing or treating psychological symptoms. This lack of specificity in the reporting points to problems that may be echoed in clinical practice: Given the heterogeneity of staffing of palliative care teams across hospitals, knowing which disciplines are responsible for which domains of care can be a challenge. Many disciplines frequently represented on a palliative care team (ie, social work, nursing, chaplaincy, physicians) have some experience with psychological distress, but it is not necessarily their primary domain of expertise, which may result in psychological symptoms going undetected and undertreated. While nurses, physicians, chaplains, and social workers certainly have experience with aspects of psychological care, in a clinical setting these providers are tasked with assessing and treating multiple domains of palliative care (eg, discharge coordination, advance care planning, spiritual assessment) and may not have the time to adequately assess for and address psychological symptoms. Furthermore, psychological symptoms may seem less pressing in the face of more overt symptoms. For example, a pain crisis or severe dyspnea may rightfully catch the eye of a provider as a more urgent issue than a patient’s depressed mood. If a patient is having severe financial concerns that threaten her ability to pay for needed medical treatment may take precedence over the patient’s anxiety about death in a social work assessment. Without a team member specifically designated to assess and treat mental health care in palliative care, it is possible, if not likely, that mental health issues are being underdetected and undertreated. Indeed, the

results of the current study indicate that many multicomponent palliative care intervention articles do not identify who on the team is responsible for mental health care. Psychological symptoms, however, deserve to be addressed even in the face of high physical symptom burden because they contribute to a patient's overall suffering and diminished quality of life. It is possible, however, that the articles evaluated in the current study are not reflective of clinical practice. Further research is needed to better capture how palliative care teams actually assess and treat mental health symptoms in practice.

In order to determine the efficacy of multicomponent palliative care in addressing psychological symptoms associated with serious illness and its treatment, valid and reliable measures should be utilized. Our study revealed that no psychological scales were utilized in *approximately 20%* of the analyzed articles. Thus, many researchers are not even measuring the efficacy of psychological interventions delivered as part of multicomponent palliative care initiatives. Furthermore, most studies only used multicomponent assessment scales but did not report subscale results, thus making it impossible for readers to understand whether psychological symptoms were being affected by the intervention. In addition, many commonly used multi-symptom assessment scales lack validity to properly screen for psychological symptoms. For example, the Edmonton Symptom Assessment Scale (ESAS), which was the most frequently utilized scale in the analyzed studies, has repeatedly been found to have only a modest or no association with the Hospital Anxiety and Depression Scale, and no valid cutoffs have been established for screening with the ESAS items on anxiety and depression.²⁵ The majority of studies did not include a specific psychological measure but did include general measures of quality of life or distress, which similarly fail to elucidate what aspects of life or distress improved as a result of the intervention. Mental health scales that have a robust evidence base for being able to validly and reliably assess psychological symptoms as well as changes in psychological symptoms were only used in 15 (25.4%) of the 59 studies. These scales included the Patient Health Questionnaire-9, the Hospital Anxiety and Depression Scale, and the Geriatric Depression Scale. Many of the studies failed to find a significant change in psychological symptoms, quality of life, distress, and so on. This finding points to the need for further research to develop interventions that can make a meaningful difference in psychological symptoms for patients with life-limiting illnesses.

Lastly, the vast majority of patients included in the analyzed studies had a primary diagnosis of cancer. Other illnesses must be included in palliative care intervention research. Symptom burden, in particular psychological symptom burden, is known to be high in patients with other end-stage illnesses such as ESRD, COPD, and Chronic Heart Failure (CHF).^{9–11,17,26} Future research on multicomponent palliative care interventions with psychological interventions must include these populations in order to ensure that palliative care is effective and available for patients with a variety of diagnoses, not just those with cancer.

Conclusion and Future Directions

There is a tremendous need for specific, well-designed research that evaluates how to effectively identify and address psychological symptoms among patients with serious illness and their families receiving palliative care. This review strongly suggests that the present

state of the science of psychological research within palliative care is lacking in rigor and specificity. The psychological sciences have amassed an impressive literature demonstrating the efficacy of various interventions to alleviate psychological symptoms such as depression and anxiety, for example, modified CBT,²⁷ meaning-centered psychotherapy,²⁸ and dignity therapy.²⁹ Palliative care researchers should draw on this literature and integrate evidence-based psychotherapies into their multi-component palliative care interventions. Indeed, every palliative care patient may not necessitate specialist psychological care; however, for those suffering from clinically significant psychological symptoms, it is essential that palliative care teams be able to identify affected patients and offer effective interventions by health-care professionals trained to provide tailored psychological interventions, not just psychosocial support. In order to provide comprehensive palliative care, all symptoms, including psychological symptoms, must be addressed by a team of health-care professionals. Currently, there is limited evidence that the care being evaluated in palliative care research is adequately addressing the psychological symptoms of patients with serious illness.

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Figure 1.

Reprinted from the adaptation of the NICE “Recommended model of professional psychological assessment and support.”^{17,18} NICE indicates National Institute for Health and Clinical Excellence.

Table 1

Scales Used to Measure Psychological Symptoms.

Scale	n	%
Multi-symptom assessment scales	32	38.9
Edmonton Symptom Assessment Scale (ESAS)	12	14.6
Functional Assessment of Cancer Therapy (FACT)	7	8.5
Palliative Care Assessment Tool (PACA)	1	1.2
Memorial Symptom Assessment	1	1.2
Functional Assessment of Chronic Illness Therapy (FACIT)	8	9.8
Symptom Check List	1	1.2
SF-18/36	2	2.4
Mental health scale	15	18.3
Center for Epidemiological Studies Depression Scale (CES-D)	4	4.9
Profile of Mood States (POMS)	3	3.7
Beck Depression Inventory (BDI)	2	2.4
Hospital Anxiety and Depression Scale (HADS)	3	3.7
State Trait Anxiety Inventory (STAI)	1	1.2
Patient Health Questionnaire-9 (PHQ-9)	2	2.4
Other	18	21.9
Quality of life measures	10	12.2
Distress measures	7	8.5
Numeric rating of sadness/anxiety	1	1.2
No scale reported	17	20.7